

VICTORIAN HEALTH AND MEDICAL RESEARCH STRATEGY

Response to the Discussion Paper

August 2015

**RESEARCH
AUSTRALIA**

AN ALLIANCE FOR DISCOVERIES IN HEALTH



About Research Australia

Research Australia is an alliance of 160 members and supporters advocating for health and medical research in Australia. Research Australia's activities are funded by its members, donors and supporters from leading research organisations, academic institutions, philanthropy, community special interest groups, peak industry bodies, biotechnology and pharmaceutical companies, small businesses and corporate Australia. It reflects the views of its diverse membership and represents the interests of the broader community.

Research Australia's mission is to make health and medical research a higher priority for the nation. We have four goals that support this mission:

- A society that is well informed and values the benefits of health and medical research.
- Greater investment in health and medical research from all sources.
- Ensure Australia captures the benefits of health and medical research.
- Promote Australia's global position in health and medical research.

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VICTORIAN HEALTH AND MEDICAL RESEARCH STRATEGY

RESPONSE TO THE DISCUSSION PAPER, AUGUST 2015

INTRODUCTION

Research Australia welcomes the opportunity to make a submission in response to the Victorian Government's discussion paper on the Victorian Health and Medical Research Strategy.

The Strategy's vision of optimising well being and improving the health outcomes of Victorians recognises the key role that research plays in delivering real benefits to the community. The objectives of embedding health and medical research in the health system and accelerating the translation of research are an acknowledgment that the vision can only be achieved through a partnership between the research and healthcare sectors.

As a key stakeholder in the funding and provision of health care, health infrastructure and research infrastructure the Victorian Government is well placed to influence the healthcare and research sectors' interactions with each other, and with other components of the Victorian economy. The ability to legislate is also critical; for example it gives the Government the ability to determine how data held in the State's public and private hospital systems is collected and used. Finally, the Victorian Government has the resources and influence to be able to set specific goals and targets and to measure progress against these.

While Research Australia agrees with the Strategy's key themes identified in the Discussion Paper, Research Australia's submission does not seek to address all of these themes or all of the questions posed in the discussion paper. Instead we have sought to respond to the questions where Research Australia is best placed to make a useful contribution.

RESPONSE TO SELECTED QUESTIONS

1. What are the areas of greatest strength in translation research that Victoria could build on and what criteria should be used to determine this?

One of the greatest strengths in translational research is the historically strong relationships between hospitals, universities and medical research institutes. Recent initiatives to strengthen these relationships provide the scope to further advance the adoption of evidence based practice.

The Victorian Government acted in 2013 to provide funding for the formation of the Monash Partners Academic Health Science Centre (MPAHSC) and the Melbourne Academic Health Research Centre (MAHRC). The importance and national significance of these partnerships was reinforced in 2015 with the announcement by the NHMRC that two of the four Australian Advanced Health Research and Translation Centres were Victorian, centred around the MPAHSC and the MAHRC respectively. In 2014, the Western Alliance Academic Health Science Centre was formed, bringing together Deakin University, Federation University and 13 health service providers operating across the western region of Victoria with a focus on improving health outcomes in regional Victoria.

Other examples of the strong links between research and health care include the new Victorian Comprehensive Cancer Centre, which brings research and health care together in the one building; the development of the Olivia Newton John Cancer Wellness Centre and Research Institute, co-located on the Austin Hospital campus in Heidelberg; and the further planned development of Monash Heart Health.

In all these cases, successive State Governments have been instrumental in supporting the co-location and integration of research and health care. Continuing to provide financial support for these initiatives is critical.

There is also a role for the State Government in bringing these Centres together to share information and perspectives on Victoria's research and health care systems; to identify shared challenges and solutions; and to share infrastructure.

Victoria has a critical mass of Australian health and medical research and of other research expertise and infrastructure. As a consequence, Victoria is well placed to undertake collaborative, interdisciplinary and multi-disciplinary research. The Victorian Government's funding commitment to the Aikenhead Centre for Medical Discovery is an example of how the Victorian Government can take advantage of the depth of research and technical expertise available in Victoria in the public and private sectors to develop new medical technologies and devices with the potential for improved health outcomes and commercial success.

On the subject of criteria, to determine Victoria's strengths, the Strategy's objectives of embedding research in the health system and accelerating translation provide a strong foundation. While these are not objectives that either the research sector or the health system can meet individually, they can be achieved when the sectors work together.

The Victorian Government is ideally placed to challenge all the Centres and collaborations which combine research and health care delivery to demonstrate:

- how they are embedding health and medical research in the health system; and
- how they are accelerating the translation of research outcomes into practice.

7. What are the barriers to translating health services research into practice and policy? How can these barriers be overcome?

Figure 4 in the Discussion Paper identifies policy and practice change as a key element of the health and medical research ecosystem leading to improved health outcomes. Policy and practice change sits at the intersection between health and medical research and health delivery, and is informed by health services research. As the Discussion Paper notes, health services research is essential to achieving the twin goals of stemming rising healthcare costs and improving health service delivery in areas where commercial drivers are lacking.

While the commercial drivers may be lacking there are still very significant financial gains to be made in the form of savings to the health system, and while health services research is an essential component to achieving change it is not sufficient in itself.

One of the barriers to translating research outcomes into practice is that in an environment where hospitals are funded on a unit cost basis, there is little incentive for hospitals to implement measures that, for example, reduce hospital admissions; and there can also be limited scope to fund 'discretionary' activities that lead to future cost reductions (and also potentially reduce hospital revenue).

As the primary provider of funding for healthcare in Victoria, the Victorian Government is the key beneficiary of measures which reduce health expenditure. In an environment in which key decisions about how, when and where to deliver healthcare have been devolved to Public Health Services, there is a role for the Victorian Government to facilitate the adoption of innovation in the form of new practices, treatments, interventions etc. and to create demand for health care innovation within the health services. There are a number of steps that need to be taken before an innovation, even if it has been proven in a clinical trial in the Victorian hospital system, can be implemented:

- Identifying suitable innovations for assessment. The starting point would be promising investigator-initiated clinical trials that have been conducted in Victoria or elsewhere. There is also scope to provide incentives for health professionals to nominate practices and/or initiatives for their evaluation through an investigator led clinical trial or by other means.
- Evaluate the economic and health benefits of implementing particular innovations. Funding for the health economics evaluation of clinical trials is not always available to researchers, and the Victorian could provide dedicated support and/or funding for this purpose.
- Assess the feasibility of introducing a new innovation into the public health system, including identifying the current work practices, systems and funding structures that pose barriers to its introduction.
- Develop implementation plans. This could include:
 - writing new guidelines and protocols,
 - training for healthcare providers,
 - providing specific funding/ remuneration mechanisms where these do not exist within the current system,
 - running a tender for a health service to operate a demonstration project etc.

There is a potential role at this stage for the Redesigning Hospital Care Program (RHCP) to support process redesign and capability building to for the introduction of new innovations.

A further barrier is the shortage of clinician researchers in Victoria's health care system. Clinicians who undertake research have a critical role to play in the interface between the research and healthcare sectors and can promote the adoption of research into practice. Encouraging clinicians in medicine, nursing and allied health to undertake higher degrees in research, 'buying out' time for research performed by clinicians and backfilling behind clinicians who undertake research in the health care system are all initiatives the Victorian Government could support to further embed research in the health system.

The Victorian Government has a key role to play in undertaking, facilitating or funding the above activities to drive the adoption of relevant research outcomes into practice across the Victorian health system.

13. There are numerous Victorian biomedical datasets held by multiple stakeholders that are difficult to access for health and medical research. How can this be addressed? (Note this question takes into consideration the privacy, confidentiality, data protection and human research ethics requirements for the use of such data.)

Research Australia supports the conclusion in the discussion paper that 'data collection without a strategic system-wide approach will result in a Victorian health system that is data rich but information poor.' There are several actions the Victorian Government can take to address this issue.

Electronic health data

There are still far too many paper based health records created in Victoria. With the forecast move to an 'opt out' model for the Personally Controlled Electronic Health Record, the impetus for electronic record keeping is building. A critical initiative which would build on and further drive this impetus would be a commitment by the Victorian Government to replacing all paper based health records in the Victorian public health system with digital records, including setting a target date for this achievement.

Privacy and confidentiality

The Australian Productivity Commission recently examined Australia's health system and identified the capacity to make much greater use of data, including through linking of data sources. The Commission also recognised that the current legislative and regulatory requirements in relation to privacy are unreasonably restricting our ability to use data for research and other purposes.

'Political will is often needed to address privacy concerns in a way that allows data to be released. Policy makers need to make trade offs between a high level of confidentiality and the consequences of *not* making data available. Concealing data can mean that patients receive ineffective (or even harmful) care, adverse effects of drugs go undetected, or significant money is spent on interventions that do not improve health outcomes (rather than on interventions that do). It can also make it difficult to hold health care providers to account for their performance.

Importantly, moving towards releasing more data does not need to mean releasing *all* data: releasing some data (with appropriate safeguards) is still better than releasing none. As a general principle, the onus should be on those who wish to withhold data to make a strong case for doing so.¹

Research Australia agrees with the Productivity Commission's position that it is possible to make sensible reforms to the current privacy and confidentiality regime which would facilitate better access for research

¹ Productivity Commission 2015, *Efficiency in Health*, Commission Research Paper, Canberra. pp.85-86

purposes while still providing appropriate protection to individuals. Rather than settling for the status quo in relation to legislated privacy requirements, Research Australia proposes that the Victorian Government support the Productivity Commission's call for reform in this area. This includes reviewing where and how the Victorian Health Records Act and other relevant laws can be amended to facilitate the use of personal health records (and other datasets) for research purposes.

Data Linking

Victorian Data Linkages (VDL), within the Victorian Department of Health, needs to be recognised as a critical component in any reform process. It can perform the vital role of linking personal data from various sources and providing de-identified data to researchers. As a part of the National Population Health Research Network, it is also able to participate in the linking of Commonwealth and State based data sets and in national research initiatives. The role of VDL could be extended beyond linking health records to include other relevant datasets (eg. prison population data).

While linking data is critical we also need to ensure that we have the data management capability to undertake the linking effectively and the data analysis capability to make the best use of it. The need for greater capability in this area, preferably through shared infrastructure and resources available to all research groups, needs to be part of the health and medical research strategy. A starting point would be to undertake a survey of the different datasets in Victoria, the entities responsible for them, and the data management capability. Any future funding for data capability infrastructure should be on the basis that it will be shared infrastructure available to all Victorian researchers (subject to research ethics approval).

16. How can Victoria work more effectively with the NHMRC and the other jurisdictions to improve the clinical trial system to be globally competitive?

The NHMRC is undertaking a program of initiatives to improve clinical trials, and clinical trials were included in the agenda of COAG's Standing Committee on Health (SCoH) in April 2014:

'Ministers endorsed work to identify ways to enhance clinical trial activity in Australia by implementing a national approach to clinical trials. They agreed to ask the Australian Health Ministers' Advisory Council (AHMAC) to conduct a scoping exercise, in consultation with the National Health and Medical Research Council, to report back on practical approaches to enhancing clinical trials activity.'

SCoH would seem to be the most appropriate forum for promoting a national uniform approach to clinical trials; however, there have been no reports to date on the progress of this initiative or the work done by AHMAC. The Victorian Government has in the past been a strong advocate for national reform through the COAG process and now may be the time for Victoria to take the lead at COAG on clinical trials reform.

19. How can the clinical registries in Victoria be better utilised for clinical trials?

Historically, clinical registries have been established for quite distinct purposes and in many cases would need to change significantly in terms of the data they collect, and their linkage to other datasets such as hospitals administration systems if they were to effectively support clinical trials. Clinical Registries are also often under-resourced in terms of their data capability and the availability of staff to deal with queries and requests for access to data.

There is scope for changes which would better align clinical registries with the information needs of clinical trials and with patient administration datasets. Research Australia suggests that this should be addressed as

part of a broader data strategy to improve the availability, utility and linkage of datasets and platforms across the Victorian health system. Please refer to the response at Question 13 under the sub-heading 'Data Linking'.

CONCLUSION

Research Australia congratulates the Victorian Government on undertaking this consultation on the future strategy Victoria's health and medical research sector. Research Australia believes the Victorian Government is uniquely placed to have a positive influence on Victoria's already significant health and medical research sector. The proposals made above seek to leverage the Victorian Government's position as a key provider of healthcare, an existing supporter of research and its ability to legislate to provide an environment that is conducive to research.

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